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ABSTRACT

The key role of the family in the growth and development of children with mental retardation is explored, from the perspective of the Central Institute on Mental Retardation in Trivandrum, India. The Institute's approach encourages the mentally retarded child to participate in all activities, within the limitations of his functional capacities. The child should not be neglected and left to fend for himself, nor should he be bestowed with too much attention and pity which may stunt his development. A properly trained, knowledgeable family can play a very effective role in making a mentally retarded person a useful member of society. To further these aims, the Institute offers a program of parent education and professional training. The Institute's approach to the education of children with mental retardation is based on the three C's--comprehension, competence, and creativity. (JDD)

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THE ROLE OF THE FAMILY IN THE INTEGRATION OF THE MENTALLY RETARDED IN INDIA

'Home, Sweet Home' goes the old adage. It is true in the case of every human being; it is more so in the case of the mentally retarded (MR). Like charity, which begins at home, the care and development of the mentally retarded child, for that matter, of every child, should begin at home. This is the basic and fundamental premise of our concept and scheme of the Total Integrated Development of the mentally retarded child which was engendered and evolved out of our experience gained in the last 17 years in running schools and teacher-training institutions in different parts of Kerala State in India.

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The family is the kingpin of all our schemes and programmes. The family and, more importantly, the parents of the mentally retarded child have to play a key role in his overall growth and development. In fact, the parents of the Mentally retarded child and the teachers of the school to which he is sent have to go hand-in-hand in giving him education and training. They have to be partners in the child's progress towards normalization and absorption in society.

We find that in his family a mentally retarded child is either neglected and disowned and left to fend for himself or bestowed too much attention, fondling and pity. Both these approaches are wrong and would only result in isolating the mentally retarded child from the family members and in turn from the society at large. The mentally retarded child will soon feel that he is either unwanted in the home or is a burden on the family. If he is too much cared for, his mortal and physical development will be stultified and stunted. And he will always start looking for a prop in all that he does and lose his capacity for self-reliance and independence in the process. The other children in the family will also resent the considerably greater parental care given to the mentally retarded child and begin to develop an aversion towards him.

The retarded child should be accepted like all the normal children in the family and encouraged to participate

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in all the activities within the limitations of his functional capacities and skills and mix freely with the fellow members on all occasions. In fact, the mentally retarded child should be treated in such a way by his family that he is not too keenly aware of his mental deformity and is able to play his role in family and society like any normal human being. He should be accepted by the family and the society like an ordinary human being, of course, lacking in full-fledged functional capacities and should never be made to feel that he is the butt of ridicule or derision in any manner.

We have formulated these views on the basis of our intimate practical experience with a number of mentally retarded children and their family situations and parental approaches.

Twenty year old Lata is one typical example of how a family's over-abundant care had made a mentally retarded child totally dependent and incapable of doing anything by herself. She was in that condition when she was brought to the Central Institute and Information Centre on Mental Retardation in Trivandrum three years ago. But, after one month at the Centre, she could take her bath herself and take care of almost all her small personal needs.

Another case is one mentioned by Dr. Glorine, a Professor in one of our Medical Schools. As a medical doctor she had sacrified her professional career in order to devote her entire time for the care of her mentally retarded child. When she found that the child's development was not upto

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expectation, she felt frustrated. A dejected parent will only further retard the growth of a mentally retarded child.

Eleven year old Unni was taken along by his parents wherever they went but soon they began to give up social visits and outings when they found that their child had become a distraction in social gatherings. Thus, the parents' withdrawal from society robbed Unni of all opportunities for social interaction and normalization.

A mentally retarded child should, however, be mentally equipped and prepared by the parents before he is given the opportunity to freely move among and mingle with people outside the family. The child should be able and confident to conduct himself well. Otherwise, such social interaction will lead to embarassing situations for the child and will bring about repulsion and revulsion in him towards others.

The home and family of a mentally retarded child is his haven and mainstay. Parental attention may make or mar a mentally retarded child's future. We have found that a properly trained, knowledgeable family can play a very effective role in making a mentally retarded person a useful and normal member of society at large. It can become the fountainhead for his efflorescence and enlightenment. Therefore, based on our findings, we have, in our Central Institute, worked out a family education programme. This programme is carried out in three different directions:

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1. During every week-end, six families from a particular region with their mentally retarded wards come to the Central Institute at Trivandrum after prior appointment with the Centre. As far as possible, the children who come at a given week-end suffer, more or less, from a particular handicap. The families attend detailed lectures by experts in different fields concerning mental retardation and view documentary films relating to the particular handicap common to the children present. The films give guidance to the families on how to handle their wards in order to achieve optimum beneficial results.

The participants are encouraged to raise questions for which clear answers are given. They also share among themselves their experiences relating to their respective wards. This interaction adds to their knowledge, gives deeper insight into their children's cases and aids in building up their self-confidence.

They are asked to write down their ideas as to how they will handle a given case and their ideas are analysed in their presence and then necessary guidance is given.

Once the families get back to their villages, a follow-up action is kept through regular correspondence. They are also encouraged to get together from time to time, preferably in one of their own houses and discuss problems concerning their wards and exchange their further experiences.

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The parents, who come to the Centre at Trivandrum without notice are also catered for. They are given the benefit of a two-hour connselling programme.

2. The second direction of our programme takes the form of one-day or two-day seminars at selected centres with the active support of service clubs and Government Health and Education Departments. Attendance by the maximum number of parents and other family members is ensured through various means including advance publicity. They are enlightened by lectures by experts and educational documentaries. Parents' sessions are an inalienable part of these seminars at which personal experience are shared. The parents are encouraged to meet again by themselves to form a working group and in the course to start an inexpensive day centre at their place. Such centres have only week-end programmes in the beginning and gradually, full week programmes are arranged. We offer to these centres the services of persons who ar have completed the one-year residential training conducted by our Central Institute at Trivandrum.

3. The trainee undergoing the one-year residential training at the Central Institute devotes one full month to move around in the villages lying around his or her own place of normal residence, visit families, identify mentally retarded persons in the area and offer specific counselling to the concerned families. Thus, counselling is carried straight into the homes of the mentally retarded and a message of hope is spread from house to hamlet. The trainee also

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encourages parents to get together, share experiences and organize and run a group centre for the benefit of their wards.

Thus, undergoing the Family Education Programme by the family of the mentally retarded child is a sine quanon for the admission of the child to our special education schools. Before a child is admitted, it is essential that his or her parents/guardians should have had the advantage of our family counselling. At the group counselling sessions, we insist on each individual parents/guardians to talk openly and exchange his experiences with the others in the group. We also offer each parent/guardian suitable guidelines based on experiences of parents in other parts of the world. And finally, when the families are encouraged to start a common Centre near their homes, their children are drawn out of the isolation in their homes and helped to mix with other mentally retarded children in the locality. The children are put through scientifically drawn training programmes designed to develop their functional levels and skills (details of which are given below) and also encouraged to participate in sports and games. Even while going to and from the common centre, the children will learn and improve personally and socially through the social integration and encounters they perforce have with different persons and situations.

At our Asha Kendram Model Normalisation Centre for the Mentally Retarded at Cochin and the Centre at Trivandrum, we are fortunate to have a good degree of parental involvement. Through that, we have succeeded in

substantially promoting the total growth of a sizeable segment of the pupils.

Our training is based on the Three C's concept. We start from the basic tenet that the world itself should be the first teacher. In our system, language is not important, perception is important. Meaningful education is imparted through the child's own multi-sensory perception and not through instruction in any language. And the total growth of the child is achieved through his functional growth. Finally an accurate assessment of the acquisition of his functional skills is made through a monitoring of his activities.

The three C's concept of education for mentally retarded is based on this approach. It consists of three stages - Comprehension, Competance and Creativity and is in shart contrast to the three R's method. The mentally retarded child, like any other child, first gets the impressions through his five senses of men and things around him within his home. He sees his mother's face which appears to him as a square. He sees her eyes as circles, her nose as a triangle and her forehead as a rectangle. He also sees the green leaves, the blue sky, the red and yellow flowers. Thus, all things around him get reduced to different basic shapes and colours or combinations of shapes and colours.

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A child's impressions of the world around him manifest in course of time in random scribblings by him on the walls, the floors, on the slate and on paper. The basic figure that first emerges from such scribblings is the circle. As time passes and the child's mind develops, he is able to the shapes of a triangle, a rectangle and a square within the circle. These shapes can be used to promote comprehension in the retarded child. This is the first step in our three C's concept.

From this, the child should be trained to move on to the second step - that of competence. Through notions about surfaces, shapes and colours, he identifies different figures and can be trained to draw a letter or two in the alphabets. Eg. A can be from the triangle, B from the rectangle and C from the semicircle. When a child understands that a triangle has three sides and a rectangle four, it becomes possible to teach him numbers. When he is able to distinguish a square from a rectangle, he can identify different lengths. Then he will comprehend linear measurements and step by step measurements by volume and weight.

We have developed several methods in the class room to enable the mentally retarded child to feel and handle the different linear shapes and three dimensional solids, mould clay, wax and plastics into different recognisable shapes and chisel shapeless wood in the carpentry shop into specific shapes. He is also made deeply aware of the differences in colour by repeatedly presenting to him a variety of colours

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and making him sit and draw or paint the various shapes using various colours.

The training is designed in several steps and stages that will help the child to comprehend more and more of every day life and develop competence through practical exercises of making coffee, cooking, home management to know the world around them through their five senses. They are taught to use all kinds of utensils, tools, gadgets and appliances to cook, to cut, chisel and saw wood, to assemble and repair a bicycle. Thus, his creative skill grows. Idea's and concepts gained through these practical exercises become part of the student's normal thinking and awareness. This method of training has been found to develop all the four cardinal human functions in the mentally retarded child namely (1) the language function or the ability to speak, (2) The psycho-social function or the ability to involve oneself in social and human activity, (3) the Motor function or the ability to move different parts of the body and (4) the cognitive functions or the ability to think discern, apprehend and know things in their correct perspective. It also enables the child to achieve functional co-ordination and help the various faculties (hearing, seeing and sensory motor) to function in unison.

The child reaches the final level of creativity

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when he or she is able to make or create a particular product on his/her own. This is the stage where he or she becomes a self-reliant and productive member of his/her community.

The success of the Three C's concept of Education in moulding a mentally retarded child into a normal, useful member of his family and society depends as much on his family and society as on his school. It should be a cumulative effort between the teacher, the parents and the neighbourhood.

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